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ABSTRACT

This paper presents a historical background and definition of Tourette Syndrome (TS), a review of the literature, and a view of the TS person as stigmatized in society. Social processes are examined through the eyes of the TS individual, and the impact of education on the TS person is examined. TS is viewed as the presence of motor or vocal tics, with the associated features of attention deficit (hyperactivity) disorder, learning disorders, sleep disorders, aggressive behaviors, mood disorders, self-injurious behavior, anxieties and phobias, obsessions and compulsions, and sensory integration problems. The literature review addresses the focus of existing research, diagnostic confusion, treatment, education, families, and social problems. Social stigma is discussed within the framework of Symbolic Interactionist theory, exploring the problem of acceptance, treatment, invasion of the private self and self development, the parental role, the educational setting, and life chances. Researchers are urged to address social issues in their research of TS; education of physicians and educators is recommended; and parents are encouraged to become advocates for their children. Appendixes list examples of motor and vocal tics, classroom strategies, causes of school problems, and phases of learning. (Contains 62 references.) (JDD)

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Tourette Syndrome and Stigma:

A Place From Which Parents Advocate

86-488

Special Project in Sociology/Anthropology

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Date: August 8, 1994

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INTRODUCTION

As a parent advocate of a child with Tourette Syndrome (TS) I have gathered information about TS so that I will be better prepared to deal with changes in my own child; thus, the personal aspect of this paper. From an academic perspective Symbolic Interaction theory has several applications to TS. Through the academic process of constructing this paper my own personal journey in exploring the world of TS begins.

I have gathered all of the information that I could from a variety of sources, such as; proceedings of the 1994 Tourette Syndrome Symposium: The Challenge of the Broad Spectrum; personal experience and communications; academic experience, and a variety of research publications, magazines, and books. This paper contains an extensive definition of TS, a review of the literature, and a view of the TS person as stigmatized in society. An examination of social process through the eyes of the Touretter and a glimpse at the impact of education on the TS person provides the parent a basic point from which to understand TS, their child, and their role as parent advocate.

Following the introduction, which includes historical background and definitions of TS, is the literature review. Subsequently, there is a discussion of TS and stigma within the framework of Symbolic Interaction theory. In closing, this paper puts forth some recommendations and conclusions. Comments and criticisms will be offered throughout.

HISTORICAL BACKGROUND

Tourette Syndrome received its name from the French neurologist George Gilles de la

Tourette who first drew the attention of the medical world to this disorder in 1885. Following Tourette Syndrome's initial presentation it was viewed as a 'moral' disorder and was seen as a psychiatric disease (Robertson, 1989; Sacks, 1992). It was not until the 1960s when the drug haloperidol was used successfully to suppress tics that TS was viewed as a "chemical disease, the result of an imbalance of the neurotransmitter, dopamine, in the brain" (Sacks, 1992), and the perspective shifted from a psychological view to a biological view (Wand, et al., 1992). But Sacks (1992) goes further in his effort to fully describe and encompass the full nature of this syndrome:

> But all these views are partial, and reductive, and fail to do justice to the full complexity of Tourette's, which may be almost as complex as human nature itself. Neither a biological nor a psychological nor a moral-social viewpoint is adequate; we must see Tourette's simultaneously from all three perspectives--as a biopsychosocial disorder (Sacks, 1992:85).

Sacks (1992) so clearly sums the tri-dimensionality of TS, including the often forgotten social aspect.

Throughout the 70s there was an emphasis on the extreme cases of TS in the literature. The 80s focused on the 'waxing and waning' and the associated disorders of TS (Bruun & Budman, in Chase, et al., 1992). The eighties also brought an increased amount of research and cooperative effort among researchers and organizations (Chase, et al., 1992). As a result there have been several changes in the understanding of TS. Golden (1990:705) emphasizes the significance of the "broadening of the diagnostic boundaries of the condition, and the association with other behavioral problems [or associated disorders]". Researchers recognize that the understanding of the disorder has been compromised by the tendency to focus on the extreme cases (Bruun & Budman, in Chase, et al., 1992).

In summary, there have been drastic changes in conceptions of TS throughout its historical

course. Viewed once as a psychological disturbance, then as a biological disorder, it is most appropriately described as a biopsychosocial disorder. The emphasis has shifted from that of severe tics to encompass the broader, often more debilitating, associated disorders.

The reader should be aware, however, that many descriptions of the disorder prevail. It is most commonly referred to as a neurochemical disorder, emphasizing the imbalance of chemical activity in the brain. However, as the spectrum broadens, other delineations also apply and are at times used singly. These may include psychological, neurological, neuropsychological, and developmental. Although collaborative research efforts are increasingly common in the area of TS, interdisciplinary, tri-dimensional views in the literature are not common.

DEFINITIONS OF TS

Unique to each individual, defining TS simply is no easy task. As Kurlan (1989) points out, in diagnosing TS, medical professionals rely on the clinical features set out in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IIIR) which include:

> (1) the presence of multiple motor tics, (2) the presence of 1 or more vocal tics[1], (3) age at onset before age 21 years, and (4) duration of more than 1 year (DSMIII-R, in Kurlan, 1989:1625).

The DSM-IIIR data are narrow and do not fully encompass the breadth of the disorder. It is the associated features which are often the cause of clinical presentation and are often more debilitating than the tics themselves (Bruun, et al., 1993:2). Thus, to fully appreciate and properly apprehend TS, a closer look at these associated features is required. Following is a brief description of each disorder synthesized from various sources as cited.

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[1]For a description of motor and vocal tics, see Appendix A.

1.) Attention Deficit (Hyperactivity) Disorder (ADD/ADHD): ADD/ADHD is characterized by difficulty in attention, impulsiveness and overactivity (Greenberg & Horn, 1991). It is common to an estimated 50% of TS patients and tends to be more pronounced with the severity of tics (Kurlan, 1989; Matthews, 1988). Compliance and task completion are difficulties both at home and at school.

2.) Learning Disorders (LD): This term encompasses specific learning disorders in the areas of written language, arithmetic, and reading (Matthews, 1988). Although LD occurs in a minimum of 35% of Touretters (Golden, 1990), there is a great deal of discrepancy and inconsistency in the literature as to a definition of LD according to Keogh (in Swanson & Keogh, 1990). What is most helpful and applicable to parent advocates in assisting their child in the educational system is the legal definition (Baillergeron, personal communication, June, 1994). It is the legal definition that carries the most weight. TS does not cause LD but the learning difficulties experienced by TS students often entail the use of assessment criteria which results in a LD classification (Hagin, 1980 & Matthews, 1988, in Harris, et al., 1989). Intellectual functioning is not usually an issue for TS children, nor is learning, necessarily, but more appropriately their difficulty is in expressing and demonstrating their knowledge (Hagin, et al., 1982). Hence, caution is advised to parent advocates in their encounters with the term Learning Disabled.

3.) Sleep Disorders: This associated feature includes "sleepwalking, increased nighttime wakening, bedwetting, [and] night terrors" (Bruun, et al., 1993:10). For the Touretter, a poor night's sleep adds to the already complicated day.

4.) Aggressive Behaviours: Tantrums and aggressive behaviour are a difficulty for approximately 25% to 35% of children with TS (Hansen, in Haerle, 1992:10). The respondents in the Canadian survey by Wand, et al. (1992) reported rates of difficulty with temper tantrums at 66.2%, and aggression at 59.3%. This behaviour occurs in the form of explosive outbursts followed by calm, reason, and guilt and remorse for the behaviour (Hansen, in Haerle, 1992). Obviously, this type of behaviour poses difficulty in the social setting as well as the family.

5.) Mood Disorders: With this associated feature the population of Touretters has a somewhat higher incidence of depression and/or mood instability. It is unclear whether these are an integral part of TS or due to the stresses accompanying the disorder and/or the immense effort involved in controlling tics (Bruun, et al., 1993).

6.) Self-Mutilative Behaviour/Self-Injurious Behaviour (SIB): In reviewing the literature, Robertson (1989) reports a range of prevalence of SIB at 13% to 53%. Compared to psychiatric populations, there is a higher incidence of SIB in TS populations (Robertson, in Chase et al., 1992). However, this author also cautions that there is a normal incidence of SIB in children, and that varying definitions exist. Parents and caregivers should assume that until proven otherwise all skin irritations and lesions are self inflicted by the TS child (Gat, personal communication, Nov., 1993).

7.) Anxieties and Phobias: School phobia is an example of this disorder and is markedly pronounced in comparison to what one may consider a 'normal' school phobia. A chronic situation develops as the individual attempts to control tics, which then results in their worsening and can be cause for

constant anxiety. There may also be a biological explanation within the causal component of TS that contributes to anxiety and phobia (Bruun, et al., 1993).

8.) Obsessions and Compulsions: Commonly referred to as Obsessive Compulsive Disorder (OCD), it "is characterized by recurrent obsessions and/or compulsions that are distressing and interfere in one's social or occupational functioning" (Leonard, et al., in Chase, et al., 1992:83). There is an estimated range of OCD in TS populations from 28% to 62% (Leonard, et al., in Chase, et al., 1992). It is important to recognize that OCD also includes obsessional thoughts which may have tremendous bearing on the development of self.

9.) Sensory Integration Problems: Such difficulties may include any of the senses of sight, hearing, smell, touch, movement, and balance, and involve the individual's ability to take in, organize and utilize this information (Papadopoulos, et al., in Haerle, 1992). An example is the irritation of fabric against the skin (Meyers, 1984). A dysfunction in this area contributes to other difficulties such as speech, muscle development, hyperactivity, aggressiveness, and learning problems (Hansen, in Haerle, 1992), as well as developmental delay in learning and interactive skills, and the hampering of self-esteem (Papadopoulos, et al., in Haerle, 1992).

The preceding descriptions encompass the breadth of this syndrome or 'spectrum disorder', so named because it is diagnosed on the basis of the features presented rather than by means of a specific test (Hansen, in Haerle, 1992; Shimberg, 1994). Considering this complexity it is not difficult to discern why TS is often misunderstood. Each of these associated disorders, alone or in

combination, combined with the degree of tics experienced by the individual, presents a portrait of personal and social difficulties in the life of the Touretter. There is disagreement among researchers as to the extent to which these associated disorders should be considered an integral part of TS (Bruun & Budman, in Chase, et al., 1992). And yet, it is imperative in analyzing TS that one look beyond the tics that constitute the DSM-IIIR criteria since,

> while in most cases tic disorders per se improve over time, a significant number of patients continue to suffer profoundly from associated disorders as well as from the social sequelae of their childhood tics (Bruun & Budman, in Chase, et al., 1992:5).

Thus, TS represents a disorder in which social stigmatization is a common daily difficulty.

LITERATURE REVIEW

As previously noted, a broad base of sources has been utilized for this project. From this base the following literature review encompasses relevant issues within the contexts of the focus of research, diagnostic confusion, treatment, education, families, and social problems.

THE FOCUS OF EXISTING RESEARCH

The TS literature available is primarily produced by researchers in the area of neurology, since the disorder has a neurobiological basis. TS is a spectrum disorder on a continuum with other disorders that are of genetic origin. From this perspective TS represents the individual manifestation on this continuum (Freeman, 1994). TS is not a 'pure' syndrome since the characteristics of TS are not mutually exclusive, but overlap into other disorders. Characteristics of TS may be found along the continuum in disorders such as ADD/ADHD, Asperger's Syndrome, Autism, mental retardation,

OCD, and anorexia (Goulet, et al., 1994). Many of the associated disorders of TS are included along this continuum. As interest in human genetics has grown, there has been an increase in genetic research in the area of TS. Thus, there is interest in TS alone, TS with the associated disorders, and the associated disorders without TS. These varying areas of interest add to diagnostic confusion. The goal of genetic research is to find the genetic cause of TS, yet this type of research does little to assist Tourette families in living their daily lives.

DIAGNOSTIC CONFUSION

Several factors have contributed to the ongoing confusion in diagnosing TS. The following discussion will demonstrate that the DSMIII-R does not adequately convey the breadth of TS between the extreme and mild cases and adds to the confusion surrounding diagnosis. 'Comorbidity' and 'ascertainment bias'[2] also add to the confusion of diagnosing the disorder and may diminish researchers' attempts to portray TS in a clear fashion.

From Extreme To Mild

As indicated in the historical background discussion there has been an emphasis on extreme cases of TS. As such, physicians hesitate or are unwilling to diagnose a case of TS without extreme symptoms. And yet it is experience due to the attention and focus of the medical research community that Cohen, et al. (in Chase, et al., 1992:342) refer to when they state that, "Because of broadened experience we no longer feel that TS is always severe, terribly impairing, or lifelong."

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[2]See page 10 for complete definitions of comorbidity and ascertainment bias.

Comings[3] (1990) speaks in terms of three degrees of TS--mild, moderate, and severe. Advances in pharmacotherapy have allowed researchers to make finer delineations of a variety of disorders, TS among them (Konstantareas, personal communication, Jan., 1993). Specifically, children presently being diagnosed with a mild form of TS would not have received such a diagnosis twenty years ago (Konstantareas, personal communication, Jan., 1993: Smith, 1989). As well, some researchers state that many mild cases exist that never come to the attention of physicians for diagnosis (Kurlan, 1989).

"[T]his raises the question of just how mild the symptoms can be and still deserve the specific diagnosis" (Cohen, et al., in Chase, et al., 1992:342). Thus, the view of TS has shifted far from the extremes to the very mild forms that may present for diagnosis. Although there are researchers who state that TS is still underdiagnosed (Kurlan, in Chase, et al., 1992; Robertson, 1989), there are researchers who state that TS is being overdiagnosed (Cohen, in Kessel, et al., 1991). Much of this confusion may be attributed to the narrow definition of the DSMIII-R. The DSMIII-R does not include the breadth of the associated disorders, nor does it adequately convey the extent of the disability in a more severe Touretter (Cohen, et al., in Chase, et al., 1992). It also does not do justice to the milder variations of TS. As well, as stated by Cohen above, there seems to be no specific line drawn at the mild end of the spectrum of TS. At some point identification of milder forms of TS must cease and a definite exclusionary line must be drawn.

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[3]I hesitate to refer to Comings beyond this paragraph. His book on TS, with an obvious focus on genetic research, is large, readable for the layperson, and is often referred to as the 'bible' on TS. Yet, during the course of my collection of research it was obvious that Comings' findings are not highly regarded by all (for example, see Robertson, 1989).

Bias

Comorbidity refers to the associated disorders that may occur along with a disorder, although they are not caused by the disorder itself (Haerle, 1992). As previously stated, it is often the associated disorders, or comorbid conditions, that lead individuals to seek medical care where TS is subsequently diagnosed. Thus, in a clinical setting, from which many research subjects are drawn, there is not only a bias toward a predominantly TS population (Bornstein, 1991; Burd, et al., 1992; Freeman, 1994), but there is also the bias of comorbidity, since an individual with one medical condition is more likely to seek medical attention for other problems (Kurlan, 1989). Cohen, et al. (in Chase, et al., 1992) describe this as a classic example of 'ascertainment bias.' Thus, research data on TS are rife with ascertainment bias due to the effects of the clinical setting and comorbidity.

At the same time, bias may also occur in the selectivity of editors in choosing submissions for publication in research journals. Often it is the more unique patient found in the clinical setting who is then written up and subsequently such an article is then selected for publication (Burd, et al., 1988). As such, the "oddities" (Burd, et al., 1988:223) become the common denominators in the research literature, and the more marginal Touretter is less likely to be noticed when presented for diagnosis. This emphasis on extremes of the condition may explain some of the problems patients experience in getting a diagnosis. It is likely that this type of bias occurs in the media where sensationalism is attractive to producers. However, this type of misrepresentation adds to the social difficulties of TS persons.

In summary, there are biases toward extreme cases and biases toward mild cases, neither of which represent an accurate portrayal of TS. Extremes exist and are disabling but these may not represent the 'normal' instance of TS. Mild cases exist but the degree to which these should be

included in the breadth of TS is unclear. Researchers need to adequately address the issue of bias and more clearly define the diagnostic framework of TS.

TREATMENT

There is as yet no cure for TS. Treatment of TS includes pharmacotherapy, counselling, team treatment and behavioural therapy.

Pharmacotherapy

Pharmacological treatment is the treatment of choice in dealing with TS. Specifically, drugs are used to suppress tics. It is not within the aims of this paper or the expertise of this writer to provide a pharmacological discussion. However, effective drug therapy requires consideration of the extent of interference from tics (Cohen, et al., in Chase, et al., 1992). Consideration of the individual patient, family, and peer situation is essential (Golden, 1990). The "whole person, and not just focusing on the total elimination of tics " (Cohen, et al., in Chase, et al., 1992:354), requires consideration. Drug therapy remains an option rather than a necessity, especially when one considers the numerous side effects of these drugs (Golden, 1990). Sacks' (1985) story entitled "Witty Ticcy Ray" is an example of an individual, who, although he experienced severe tics, chose to relinquish medication on weekends to fully experience 'his self'. As such, pharmacotherapy does not in any way represent a cure and has a variety of limitations that need to be considered.

Counselling

Beyond drug therapy it "is vitally important" to provide counselling to individuals, families,

and teachers to assist them in understanding and managing TS (Robertson, 1989:161). In discussing treatment approaches Cohen, et al. (in Chase, et al., 1992:354) recommend psychotherapy, psychosocial therapy, family psychoeducational help, family therapy, and academic intervention, as may be indicated. Similar recommendations for counselling are found throughout the literature (Singer & Rosenberg, 1989; Wand, et al., 1992).

Team treatment

Considering the tri-dimensional conception of TS and the broad impact of the disorder on one's life and family, a multidisciplinary team treatment is ideal (Burd, et al., 1992). Such a team presented their in-service school program at the 1994 TS Symposium. Their team, from St. Boniface Hospital in Manitoba, includes an educator, a nurse, and a psychiatrist. Their clinical setting allows them access to occupational therapists and social workers as well (Goulet, et al., 1994). This multidisciplinary team approach is used internationally and in clinical and support group environments (Robertson, 1989), but may not be available in less populated areas.

Behavioural Therapy

According to Robertson (1989), prescriptive behavioural therapy has proven to be of little value, while Burd & Kerbeshian (in Chase, et al., 1992:312) call for an increase in "positive reinforcement behavior management programs targeting individual behaviors". Yet, Burd, et al. (1988) also describe instances of increased tics in the use of behavioural management strategies. Thus, caution is advised in consideration and implementation of behavioural management programs. It is suggested by Baer (in Chase, et al., 1992) that behavioural therapy may be useful for TS

patients with Obsessive Compulsive Disorder. Consistent, predictable parent strategies are essential (Parker, 1985; Wand, et al., 1994b), because structured guidelines, like routines, are beneficial to these children (Fruchter, 1994).

EDUCATION

Issues that pertain to education of children with TS include; a discrepancy between the amount of literature and individuals' experiences; academic ability; individual accommodation; the impact of the associated disorders, and classroom provisions.

Literature Versus Experiences

Although there was, in the eighties, an inadequacy of educational literature in regard to TS (Bauer & Shea, 1984; Stefl & Rubin, 1985), there is a substantial amount of information to be found today. However, the experiences of Tourette families support the view that there is inadequate knowledge about TS in the educational system. Shady, et al. (1988) report that 70.4% of survey respondents rated their schools as 'not at all' knowledgeable about TS. This gap between the amount of literature and practical experiences of families represents a communication disparity and may point to an 'accessibility-to-information' issue.

Academic Ability

Academic problems for TS students are common, yet intelligence is not an issue in the majority of cases and giftedness is not uncommon (Stefl & Rubin, 1985; Wand, et al., 1994a; Wertheim, 1993). The major difficulty lies in a discrepancy between academic performance and

capability (Harris, et al, 1993; Parker, 1985; Shady, et al., 1988). Burd (in Haerle, 1992) states that educational difficulties in TS students peak between the ages of eleven and thirteen and are followed by a gradual decrease in difficulty. The literature often attributes the difficulties in academic achievement to visual-motor impairment (Harris, et al., 1993), although this finding is not universal (Dykens, et al., 1990). Harris, et al. (1993) did not find a single origin for the visual-motor impairment but variation in cause and characteristics among study subjects. Hence, there are many factors that contribute to academic difficulties with no single cause as yet distinguished.

Individual Accommodation

Considering the uniqueness of each individual Touretter, researchers emphasize that the most important component of educational success is individual accommodation (Burd, in Haerle, 1992; Davidovicz, 1994:2). Since the nature of TS is so variable, one must be aware that, "[t]here is no one 'Tourette Syndrome IEP' [Individual Education Plan] which will work for all students with TS" (Fisher, 1991:8). Individual accommodation is the wish for every child's educational success. The survey results of Shady, et al. (1988) indicate that the majority of TS students attend the regular classroom. Considering the large number of students in most classrooms and the burden on most teachers it is not always clear in the literature how one teacher can implement all that may be required to accommodate one individual. However, the ultimate goal is to implement "creative solutions (specific to the child in question) which can help reduce stress and feelings of failure" (Davidovicz, 1994:2).

Educators need to be aware of the common classroom difficulties that may be experienced by the TS student. These may include Kurlan's (in Chase, et al., 1992:76) "Causes of school

problems in Tourette syndrome" contained in Appendix B. Also covered in the discussion of school problems are the psychosocial aspects such as depression, lack of self-confidence and social isolation--all of which may contribute to academic failure (Kurlan, in Chase, et al., 1992).

The Impact Of The Associated Disorders & Classroom Provisions

The associated disorders involved in TS contribute the greatest impact on education, often directly affecting student's learning as is the case with Learning Disabilities and Attention Deficit (Hyperactivity) Disorder. In order to deal with classroom difficulties provisions to accommodate the TS student may include those set out by Connors (1994).[4] Note that these accommodations encompass many of the associated disorders. In interpreting and applying guidelines and suggestions presented in the literature one must consider that their success has not been scientifically confirmed (Shady, et al., 1988).

FAMILIES

The following discussion of the literature on TS families addresses the lack of research on, and importance of, families, tasks of the family, and family stress.

Research And The Importance Of The Family

There appears to be a marked lack of research in the area of TS families. And yet, many Touretters exhibit their most marked symptoms at home (Hubka, et al., 1988; Meyers, 1984). A

[4]See Appendix C, "Specific Classroom Strategies and Techniques for Students with Tourette Syndrome".

disorder affecting one in a family unit ultimately has a 'system effect' which impacts upon all of the unit's members. In this respect the disability aspect of TS is similar to that of other disabilities.[5] Family research is also important since families provide children with meanings and information about themselves. As a starting place for human growth, research in TS families should be a priority.

Tasks Of The Family

Harper (in Chase, et al., 1992:320) discusses the tasks of the family in terms of sequential phases; prediagnosis, diagnosis, wound healing, and adaptation. In the prediagnosis phase the family's task is to recognize that the child has a problem. The diagnosis phase "constitutes an injury" (Harper, in Chase, et al., 1992:320) with which this family must grapple. The third phase, wound healing, represents a loss of dreams and is confirmed by Hubka, et al. (1988). It is in this stage that a family experiences a process of grief and must come to terms with the affects that TS has and will have on their lives. The final phase, adaptation, represents, "a variant on the need of every family to help a child learn to take responsibility" (Harper, in Chase, et al., 1992:320). In adapting, the family must adjust and move on. For this family to succeed, the child's TS must not remain a focal point of family functioning (Wand, et al., 1994b).

Family Stress

The family living with TS experiences several stresses above those experienced by 'normal'

[5]Readers may find it beneficial to read further in the area of other disabilities for information pertaining to disabled family issues.

families. One difficulty reported by parents is in differentiating 'normal' childhood behaviour from TS behaviour (Cohen, in Kessel, et al., 1991; Hubka, et al., 1988). Another difficulty is the social unacceptability of tics, especially tics like spitting and swearing (Hubka, et al., 1988). This type of stress often leads to a third stress--isolation. Isolation itself often results from TS behaviour that leads to the inability to acquire a babysitter. As well, TS children often have few if any friends due to their aggressive behaviour, socially unacceptable tics, and lack of social skill (Hubka, et al., 1988). All of these stresses, as well as the process of coming to terms with a child with TS, add to marital stress. Often spouses blame each other for the genetic origin of the disorder. Sexual relations may become strained for fear of producing another TS child (Hubka, et al., 1988). A mother may be more adversely affected than a father since many of the new advocate duties, such as liaising with the school, become hers (Hubka, et al., 1988).

A stress often overlooked is that upon siblings who do not have TS (Hubka, et al., 1988; Parker, 1985). The literature on children with disabilities and handicaps, such as that available through the National Information Center for Children and Youth with Disabilities (NICHY),[6] indicates that this has become a prominent area of concern, and so, too, should be addressed specifically for TS families.

SOCIAL PROBLEMS

Within the social aspect of TS, the importance of social adjustment is often overlooked. As well as those factors previously mentioned, others contribute to the poor social functioning of persons with TS. These include a lack of research, poor peer relations, tic treatment assumptions,

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[6]NICHY, P.O. Box 1492, Washington, DC, 20013-1492

social skill delay, and a lack of understanding by others.

Importance Of Research

Researchers who are addressing the social issues confirm the long term importance of these issues as TS children are at risk for later adjustment problems (Bawden, 1994; Parker, 1985). The literature is very limited in addressing the social problems associated with TS (Shady, et al., 1988). And yet, the social problems are admittedly a prominent difficulty for those with TS and their families.

> Of great immediate concern are those psychosocial conditions that result from lack of awareness and bias. The suffering and stigmatization that emanate from such conditions include harsh punishment and abuse, social ostracism, and the labelling effects of being considered mentally incompetent (Earls, in Chase, et al., 1992:58).

Thus, it seems that, although the social difficulties are considered a relatively integral part of the disorder, few researchers address this issue directly.

Peer Relations

Those researchers addressing the social import of TS are aware that poor peer relations are predictors of school dropout, juvenile and adult crime, and adult psychopathology, and thus focus their research in the area of peer relations (Bawden, 1994). Ratings by fellow students and teachers indicate that TS children are more aggressive, more withdrawn and less popular than their peers (Bawden, 1994). However, children with more severe tics unexpectedly did not have poorer peer relations ratings in this study (Bawden, 1994). This finding was unexpected since it is generally agreed upon by researchers that the severity of tics is a predictor of other behavioural and emotional difficulties, and thus, social success (Bawden, 1994; Bruun & Budman, in Chase, et al., 1992).

Thus, researchers seem to focus on tic severity as a predictor of social adjustment while findings such as Bawden's (1994) fail to show this. Perhaps this is indicative of a need to more adequately surmise the degree of social difficulty and then attempt to determine predictors.

Tic Treatment

Clinicians generally treat the tics of their TS patients. They then assume that this will subdue social difficulties. However, Bawden (1994) reports that in comparisons, ratings of TS children by their clinicians and their peers are dissimilar. Thus, although tic control contributes to a reduction in the social interference caused by tics, the reduction of tics is not necessarily an indicator of social adjustment.

Social Skill Delay

TS children often exhibit a delay in their social skills development. It is unclear if this is primary to TS or secondary to the stigma attached to Touretter's (Dykens, et al., 1990).

Lack Of Understanding

From a psychosocial perspective the social difficulties that occur for Touretters are due to a lack of understanding (Goulet, et al., 1994). The Tourette Syndrome Foundation of Canada and the Tourette Syndrome Association in the United States are primarily concerned with educating to increase awareness of TS and reduce the lack of understanding. This lack of understanding is not strictly limited to the public. These organizations extend their wealth of information to doctors, educators, parents, families, individuals, law enforcers, insurance agencies, and the public.

This lack of understanding is still quite apparent within the medical profession. Although some of the diagnostic confusion is responsible there is a general lack of knowledge about TS in the medical community at large. For example, in the past medical school textbooks contained no more than one paragraph describing the disorder (Freeman, 1994). This shortage of medical awareness directly affects TS persons and their families as they struggle to obtain a diagnosis and adequate care. Such struggles are explicitly described in publications such as those by Haerle (1992), and Seligman & Hilkevich (1992).

One publication provided by the Tourette Syndrome organizations is information for teachers to diagnose TS in the classroom. The experience of one researcher has been that on occasion when providing in-service programs in schools he has noticed other children that fit the diagnostic criteria for TS (Goulet, et al., 1994). In a 1985 publication it was stated that, "With the increase in public awareness of Tourette Syndrome, approximately 86% of the cases are diagnosed correctly by teachers, parents, other relatives, or friends of the family before first being seen by a neurologist" (Parker, 1985:30). These examples are a poor reflection on the medical profession where persons seek understanding, compassion, and knowledge.

TOURETTE SYNDROME AND STIGMA

As indicated in the preceding discussion, there are numerous factors which contribute to the social difficulties of the Touretter. By applying the Symbolic Interactionist theory used by Goffman (1963) in his work on stigma, the social processes of TS and stigma will be analyzed. This

discussion will address stigma and the problem of acceptance, treatment, invasion of the private self and self development, the parental role, the educational setting, and life chances. Goffman's work on stigma is considered classic and although written over thirty years ago, it is still a very useful tool for analyzing the sociology of illness such as TS.

STIGMA & PROBLEM OF ACCEPTANCE

Goffman's (1963) studies of stigmatized individuals were an elaboration of the "central feature...'acceptance'" (Goffman, 1963:8). The view that those with TS suffer most profoundly from a lack of acceptance and/or understanding is supported in the TS literature. One writer states that, "[t]he single biggest difficulty for people with TS is social acceptance" (Tourette Syndrome Foundation of Canada, date unavailable:1).

Tourette Syndrome fits into Goffman's (1963) work since it falls within the legal categorization of a disability (Tourette Syndrome Association Inc., 1991). The legal disability categorization of TS indicates the 'stigma symbols' of TS. The Touretter's verbal and motor tics are the central stigma symbols which "[draw] attention to a debasing identity discrepancy...with a consequent reduction in our valuation of the individual" (Goffman, 1963:43). Although one may consider other features of the disorder to contribute to social stigmatization of the Touretter, for the purposes of this discussion the focus will remain primarily around the stigma symbols of tics.

As the breadth of TS continues to encompass the increasingly mild forms of TS, one wonders if this is an instance of "rampant 'medicalization'" (Conrad & Schneider, in Rosenberg & Lewis, 1993:15) and "biological determinism" (Rosenberg & Lewis, 1993:15). However, for Touretters whose tics are obvious stigma symbols, Rosenberg and Lewis (1993) clarify that the biological or

constitutional cause of TS is separate from the behaviour. Their example of coprolalia indicates that although the cause of the shouting is neurological, "what is shouted is not. Nor is the societal response" (Rosenberg & Lewis, 1993:144). Thus, although one might consider that there is a tendency toward medicalization (which is confirmed by researchers who suggest that TS is overdiagnosed), TS behaviour and the ensuing social processes are sociological, not biological.

TREATMENT

Goffman (1963) describes efforts made by the stigmatized in 'covering' their stigma to restrict their display, reduce tension, and withdraw attention from the stigma. The method most often used to treat TS is pharmacological suppression of tics which in itself is covering the stigma. Drug treatment is often instigated just for the reasons cited by Goffman (1963); to reduce the social stress of exhibiting tics. Voluntary suppression for short periods of time is also possible and is characteristically an effort to delay the need to tic (Papadopoulos, et al. in Haerle, 1992). The availability of a time-out space in school is often suggested to allow the student a safe place in which to let tics go (Burd & Kerbeshian, in Chase, et al., 1992; Connors, 1994). Thus, voluntary or pharmacological tic suppression are forms of covering the tics which lead to stigma. By covering the tics there is a lessening of social reaction and thus, stigma. In terms of covering and labelling doctors may be seen as enforcing stigmatization through pharmacological suppression of tics. This is not to devalue pharmacological intervention but merely to recognize the social process in practice. One is reminded again of Sacks' (1985) "Witty Ticcy Ray" who felt that drugs not only suppressed his tics but 'his self'. In order to fully express 'his self' he bravely 'allowed' the expression of his tics, 'his self', at the risk of ostracism.

SELF DEVELOPMENT

According to Stark (1992:75), since "the **self** is our learned understanding of the responses of others to our conduct", the Touretter, whose conduct is viewed as not 'normal', experiences difficulty in self development. One Touretter states, "[w]herever I go, I'm reminded that I do something that makes people uncomfortable. Which makes me uncomfortable" (Melbye, in Seligman & Hilkevich, 1992:160). This statement epitomizes the cycle by which the TS individual presents him/herself socially, recognizes that he/she is not 'normal', and experiences stress, which likely exacerbates the tics. In this cycle, the Touretter's reflected self is constantly depreciated. Within the framework laid out by Goffman (1963), the Touretter with obvious tics is both a 'discredited person'--experiencing an obvious differentness with tension to manage--, and a 'discreditable person'--he/she must manage information about his/her failing (Goffman, 1963). It is the former, the discredited identity, which plays the greatest part in hampering self development of the Touretter, although both aspects contribute. Thus Melbye, the uncomfortable Touretter, possesses tics that initiate a cycle of discomfort that he must constantly manage.

As stigmatized individuals experience the phases of adjustment addressed by Goffman (1963)[7], they reach a phase whereby they attain a degree of self acceptance and self respect. At this point the stigmatized will no longer feel the need to conceal their failing. However, this phase may not be attainable for the Touretter. A recent survey of adults with TS indicates that they,

> ...have lower self-concept (one's perception of oneself, based on one's interaction with one's environment) and higher levels of social anxiety and public self-consciousness (the attention one pays to how one is viewed by others in a social setting) than the general population (Tourette Syndrome Foundation of Canada, Summer 1992:1).

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[7]See Appendix D for a brief summary of "Phases of Learning Experienced by Stigmatized Individuals".

Note that these definitions fall within the Symbolic Interactionist ideas of self development. Seligman (1992) conveys the personal battle of self when he states, "Dignity. How does one live with dignity when you spit constantly, swear involuntarily, and cannot control your movements?" (Seligman, in Seligman & Hilkevich, 1992:187). Such tics as spitting and swearing are not considered 'normal.' Social expectations force Touretters like Seligman to constantly attempt to behave in a 'normal' manner. These social expectations affect his own personal concept of dignity. It is unclear how the Touretter can build the self concept necessary to develop beyond the necessity to conceal his/her stigma from 'normals.'

INVASION OF THE PRIVATE SELF

Several researchers point out the invasiveness of TS upon the individual's self. Unique for each individual, TS care involves a microscopic analysis of one's behaviour, thoughts and motivations; "What is normally private--the child's [or adult's] inner life and feelings--becomes clinical data" (Cohen, in Kessel, et al., 1991:172). In discussing the implications of professional advice for dealing with one's stigma, Goffman (1963) notes that this counsel pervades the personal and private life of the individual. Thus, there are researchers and sociologists who recognize the violation of self that occurs for TS individuals. Yet few, if any, have blended the concept of poor social development recognized by TS writers with the actual of social processes of stigmatization detailed by sociologists like Goffman.

THE PARENTAL ROLE

Goffman (1963) recognizes that in the social interplay between the stigmatized and 'normals', "intimates can come to play a special role" (Goffman, 1963:55). It is here that the parental role

of advocate is apparent and that, although, "their acceptance of him [sic] is not influenced by his stigma, their duties will be" (Goffman, 1963:55). Thus, a parent who fully accepts their child and his/her disorder without being influenced by the child's stigma is none the less directed by the stigma around TS to act on behalf of their child. In accepting their child's disorder, it is advisable that parents not change their expectations of their child. Although the expectation of 'normal' behaviour from a TS child varies with the severity of the disorder, families where the TS child is expected to behave 'normally' appear to have better adapted TS children (Cohen, in Kessel, et al., 1991; Hubka, et al., 1988; Shimberg, 1994). This expectation of normalcy is complicated since parents often report that it is difficult to distinguish between TS behaviour which should be accepted as involuntary, and 'normal' childhood misbehaviour (Shimberg, 1994). Thus, the challenge for the parent is in balancing normal expectations with the TS knowledge which pertains to their individual child.

Goffman (1963) warns against leaving the child in ignorance in regard to his stigma. Hence, we address the intimate role of the parent advocate. Since families give all children their first reflected meanings of themselves (Harper, in Chase, et al., 1992), it is imperative that parents educate their child about their disorder. In this respect, parent advocacy in the domestic sphere entails assisting the discredited TS child in managing the tension surrounding his obvious differentness and in preparing him/her for the repercussions that may ensue in the presentation of his social identity. This role, if left unfulfilled, leaves the child unaware of the stigma he/she may encounter, and, therefore, more vulnerable to the hostility of the public sphere (Goffman, 1963).

EDUCATIONAL SETTING

Further to the domestic advocate role in terms of managing the tension of their discredited child, parents must also advocate for their child in the public sphere in terms of managing this child's stigma. Since the child's 'work' is in the school environment much of the literature and the need for advocacy focuses here. As well, the educational experience the child receives has life-long implications for his/her development and success. Since the social identity portrayed by the TS child is influenced by his/her tics, the parent advocate educates others in regard to the personal identity of this child so that others "know" (Goffman, 1963:66). Goffman (1963) cites school entrance as often the first occasion of stigma learning for the stigmatized. By educating the teacher and others surrounding the child, including peers, the opportunities for acceptance of the TS child are increased.

LIFE CHANCES

Goffman (1963) describes the socially stigmatized as suffering from a reduction in life's chances. Social processes stigmatize individuals. The TS literature supports the view that social processes hamper TS persons; "People with Tourette have contributions to make to society, but society must let them" (Wertheim, 1993:18). The disorder of TS or any other disorder is not in itself stigmatizing.

Although this discussion has focused on the 'stigma symbols' of tics, tics themselves and their severity do not represent adequate predictors of social adjustment (Stokes, et al., 1991). It is suggested that even mildly affected Touretters be assessed for social adjustment (Stokes, et al., 1991). Furthermore, the associated disorders tend to indicate more long term difficulties, as

previously discussed. As well, the associated disorders result in labels which are often applied to these individuals in the educational setting.

Labelling in itself has been shown to result in the labelled person growing into their label. As such, the label defines the deviant behaviour, which is "socially defined and socially created" (Rosenberg & Lewis, 1993:123), and is reflected back to the individual as what he/she 'should be.' Diagnosis itself is a process of labelling (Rosenberg & Lewis, 1993) and in helping TS children to grow, parents, especially, need to be aware of this. Hence, parents' expectations of 'normally' labelled behaviour, not TS labelled behaviour, can assist the TS child in developing as 'normally' as possible.

Further to the labelling process is 'secondary deviance' which is behaviour that is a reaction to having been labelled as deviant. Labels have been shown to limit economic and occupational opportunities, interpersonal relations, and self concept (Stark, 1992:197).

RECOMMENDATIONS

Throughout this paper the prominent issue has been social adjustment. To accurately assess TS one must include the social dimension. It is the social dimension that affects the lives of Touretters and their families on a daily basis. There is marked lack of research addressing social issues. Considering the daily importance of this issue it should receive the primary attention of

researchers.

Considering the breadth of the disorder, the all-encompassing nature of care required by physicians, and the still-apparent shortage of well-informed physicians, it is imperative that education of physicians remain an ongoing process. Although the TS foundations make this information available in a variety of forms, physicians must attempt to keep themselves informed. The physician willing to take on a TS patient must constantly keep abreast of the variety of information that will enable his/her patients to live better lives. Harper (in Chase, et al., 1992:321) states that, "no conditions require clinicians to carry out a broader range of professional activities than does TS." It would be wise for parents to consider assessing their physician in terms of the physician's tasks laid out by Harper. Physicians are human too, and often laypersons hesitate to approach physicians with new ideas and honest queries. As iterated by Burd & Kerbeshian (in Chase, et al., 1992:316), "[i]n the absence of a cure and given the limitations of pharmacologic interventions, we must expand our research into the appropriate management of these most vulnerable persons with TS" (Burd & Kerbeshian, in Chase, et al., 1992:316). Further to this suggestion, the management of TS persons must focus more on social adjustment issues.

Although information is available, and considering that each TS student is unique, educators must be informed about TS by parents and physicians. This is not to excuse educators' lack of information. However, it is likely that physicians and parents will have a better conception of what may be required for the individual Touretter. As such, liaising with the school is a constant duty of parents, and should be part of the physician's duties as well. In this manner, there may be a narrowing of the gap between the amount of information on the education of TS students and experiences.

In gathering information for this project I was surprised with the amount of data available. However, the emphasis of this data is clinical research material and is not readily available or readable by the lay population. Haerle's 1992 publication subtitled A Parent's Guide is invaluable. Canadian readers should be cautioned that not all of the educational material is applicable to their child. As well, it is worthy of note here that each school board has its own separate policy on special education. However, each board is still governed by educational law. It is up to parents to find out what those laws and policies are and advocate on behalf of their child for their implementation. Neither the law nor school board policies are always readily accessible. Parents are advised and encouraged to ask questions and get answers. It is suggested that the same questions be asked of numerous people and the varying answers synthesized.

As indicated in the literature review, there are several important issues for researchers. It is recommended that researchers make an effort to clarify discrepancies over a definition of TS and its breadth. As well, although research is being directed toward clarifying whether or not the associated disorders are actually part of TS, I find it difficult that anyone could consider a discussion of TS without their inclusion. Some consensus on this issue would assist future discussions of TS.

CONCLUSION

In reviewing the literature and drawing together the many facets of TS a current encompassing definition of the disorder has been presented. TS is more than a neurochemical disorder. It is a condition that disturbs the daily functioning of children, families, and adults. As such the social implications are perhaps as multi-faceted as the disorder itself.

The sociological analysis of TS in terms of stigma has implications beyond this one disorder. As such this analysis can be imposed on other disabling disorders, ailments and situations.

From here, readers who are parents of TS children can assess their roles as advocates from a more sociological perspective. Parent advocates must educate themselves about TS and their children's educational and socialization processes. This paper is perhaps a starting point from which a parent advocate might begin to understand TS and implement his/her role. TS can be understood. By addressing the issues most pertinent to the daily development and growth of our children--the sociological and educational implications of TS--parents and others can better understand TS and improve the lives of TS persons.

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APPENDIX A

Examples of Common Motor and Vocal Tics
(Adapted from Hansen in Haerle, 1992:4.)

Motor Tics

Simple

blinking eyes
jerking neck
shrugging shoulders
grimacing
flipping head
kicking
tensing muscles
sticking tongue out
finger movements

Complex

facial gestures (eye rolling)
grooming behaviors (smoothing hair)
smelling things
touching
jumping
hitting
biting
echopraxia (imitating others' actions)
copropraxia (obscene gestures--giving the finger)
self-injurious behaviors (picking scabs,rubbing sores raw, mouth biting, hitting self)

Vocal Tics

Simple

throat-clearing
sniffing
coughing
grunting
spitting
yelling
belching

Complex

animal sounds
repeating words or phrases out of context ("Oh boy," "I don't know," or words from advertising jingles on TV)
coprolalia (using obscene or other socially inappropriate words)
palilalia (repeating one's own words or sounds--"Do my work, work, work")
echolalia (repeating the last sound, word, or phrase spoken by another person--saying "Come over here" after mother has just said, "Come over here")

APPENDIX B

Specific Classroom Strategies and Techniques for Students with Tourette Syndrome

by **Susan Conners, M.Ed.**

For Tic Symptoms

Testing modifications: test in a separate location. Stress often aggravates TS symptoms and taking tests is always stressful. Waive time limits on tests.

Give the child frequent breaks out of the classroom to release tics. Send him/her to the lavatory, drinking fountain or on an errand.

Educate the other students who come in contact with the TS child. The school psychologist, the school social worker, the school nurse or an advocate from the local Tourette Syndrome Association can be helpful here.

Provide a refuge where the student may go when tics become severe or when he/she is in need of a release. For example: Nurse's Office, Resource Room, or School Psychologist's Office.

If tics are socially inappropriate (spitting, swearing, touching other people in inappropriate places), it may be necessary to brain storm possible solutions which could include tic substitution. For example, a child whose tics include spitting might carry a tissue to spit into. A child who exhibited inappropriate touching was able to touch an elbow rather than a more inappropriate place.

For ADHD Problems

Many TS students have indicated that center front seating becomes a source of embarrassment because of tics. Preferential seating is advisable – to the side and front of the classroom, away from distractions. In this way, the teacher can provide special attention for instructions/directions and enable the student to refocus when necessary.

Quiet place to work in the classroom: consider allowing student to wear headset with instrumental music in corner of the room to block out distraction.

Change tasks frequently.

Allow for freedom of movement. Often giving the child an eraser or a small squeeze toy to fidget with during times when concentration is needed, helps the child to better focus and sustain attention.

Moderate structure and routine with flexibility is the key to working with most TS children with ADHD.

Break down assignments, for example, avoid giving more than one paper/ditto at a time. One effective approach is to fold the paper in half and have the student come up to you when finished with that portion and then take a break before continuing.

Break down all the long range assignments and projects. Give shorter time frames. For example, Part I is due in two days, rather than the entire project due in three weeks. Three weeks may seem like a lifetime.

Establish a hand gesture or signal which becomes a reminder to refocus during listening periods.

Provide a daily assignment sheet to be filled out by the student, signed by the teachers and verified by parents each evening. Teacher's signature will verify that the assignment was recorded correctly by the student.

At the end of the day, allow student to leave class 2 to 3 minutes early to pack schoolbag with appropriate materials in the hallway when he/she is alone and not disturbed by crowds of other students. When possible, have an aide, consultant teacher or resource room teacher check out the student to make sure necessary supplies are packed.

Penalizing students who constantly forget or lose supplies is ineffective. Keep a supply of pencils, paper, etc. or have parents supply these items for you to keep in a desk drawer for student when he/she forgets or misplaces them.

Having an extra set of textbooks at home is helpful so that the student need not worry about forgetting necessary books each day.

Color code texts with notebooks and folders. For example, blue science book goes with blue notebook and blue folder.

Implement a behavior modification program which will help control child's impulsivity. TS children with ADHD often blurt out answers, leave their seats without even realizing it, and have difficulty waiting their turn. While we need to allow for some of this, the child cannot be allowed to disrupt the class and infringe upon other students' right to learn. I assign students Bingo chips, baseball cards, or whatever the student is interested in or is appropriate to the age level. These are given each class period and removed one at a time after two or three of the above behaviors are exhibited. A reward should be given for the number of objects left each day or week. It should be noted that behavior modification techniques will not help to reduce the tics or vocalizations and may or may not be helpful for the OCD behaviors.

Reduce the length of homework assignments. For example, do every other problem or only 5 of 10 assigned questions.

For Visual Motor Integration — Auditory Processing Difficulties, Fine Motor Skill Problems

The use of a word processor

Occupational Therapy

Note taker or the use of a tape recorder

Tests administered orally

Reports given orally

Verify all homework assignments copied from the blackboard or from teacher's oral instructions

Shortened assignments

Standardized test answers written in test booklet and recopied later onto answer paper by a teacher aide

Waive time limits on tests

Do not penalize student for poor handwriting. In elementary grades, where students often receive a handwriting grade, base grade on effort

Do not penalize for spelling errors. Encourage the use of spell check on a word processor

Use visuals and verbal directions in addition to written instructions

Give clear, simple directions one or two steps at a time. Have student repeat directions back to you

Allow the student a place to go where he/she will not disturb others to quietly repeat or go over instructions

Provide graph paper to help line up math problems

For Short Fuse and Oppositional Behavior Difficulties

Children with TS and ADHD are very easily frustrated. They live day in and day out with a disorder that never allows them to be still. Their bodies are constantly out of their control. Their bodies constantly hurt from the persistent tics. It takes very little to set these children off. They are also very easily over stimulated by large crowds, noisy situations and disorganization in the classroom. Some of the most difficult times for these children can be in the hallways between classes, in the cafeteria and on the school bus. Not only are these noisy, unstructured situations, there is also less, if any, adult supervision. Some possible interventions are:

- Allowing the child to leave the classroom 2 to 3 minutes early to avoid crowded hallways;
- Having a teacher aide nearby in the cafeteria and hallways to prevent the possibility of confrontations rather than having to break them up after they occur;
- Up front seating on the school bus;
- Educating the bus driver;
- If misbehavior on the school bus is especially problematic, the student may do better on a smaller bus for special education students.

Remember

TS children don't want to be out of control. They don't know how to avoid situations that cause this to happen. We need to help them with this lack of impulse control. This is not always an expression of bad behavior, rather it may be an expression of neurobiological disturbances.

Medications

Many TS children take medication. The majority of these medications have side effects which may affect their performance and behavior in school. It is most important for the school nurse to become involved in informing teachers not only about the medications being taken, but about the possible side effects of these medications.

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APPENDIX C

Causes of School Problems in Tourette Syndrome
(Adapted from Kurlan in Chase, Friedhoff, & Cohen, 1992:76, Table 1)

Primary TS symptoms

- Motor tics (including excessive touching)
- Vocal tics (including echolalia, coprolalia)
- Mental "energy" expended in suppressing tics

Obsessive-compulsive behavior

Attention deficit hyperactivity disorder

Other behavioral disturbances

- Primary school and other phobias
- Testing anxiety
- Conduct disorder
- Anxiety disorder
- Depression
- Short temper, argumentative personality traits

Neuropsychological/cognitive disturbances

Poor socialization skills

Low self-esteem

Medication side effects (including sedation, depression)

APPENDIX D

Phases of Learning Experienced by Stigmatized Individuals
(Adapted from E. Goffman, 1963.)

Goffman puts forth a process by which the stigmatized learn to deal with their identity. Briefly, this process involves the following steps;

1. Learning the normal point of view.
2. Learning that he/she is disqualified according to the normal point of view.
3. Learning to cope with how others treat him/her.
4. Learning to pass.
5. Learning to be above passing having attained a degree of self acceptance and self respect, and no longer needing to conceal his/her failing.